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## **Genetic Privacy, Discrimination and Research in Washington State: Findings, Conclusions and Recommendations of the Washington State Board of Health Genetics Task Force**

### **Executive Summary**

The Washington State Legislature recognized a need to evaluate the State's policies regarding genetic privacy and discrimination and to assess the potential affect of new policies on individuals' privacy and civil rights and research and development in the use of DNA to promote public health, safety and welfare. This recognition led to the passage of Engrossed Substitute Senate Bill (ESSB) 6153 Section 220.8, which directed the State Board of Health (SBOH) to convene a broad-based task force charged with reviewing "the available information on the potential risks and benefits to public and personal health and safety, and to individual privacy, of emerging technologies involving human DNA". Pursuant to this mandate, the Board established the Genetics Task Force (GTF) in October 2002. The 22-member GTF comprised representatives from a variety or professional, consumer, and public organizations and held five public meetings between January 2002 and September 2002. During this time the Task Force received and evaluated information pertaining to four areas identified by the Legislature: a) the incidence of discriminatory actions based upon genetic information; b) strategies to safeguard civil rights and privacy related to genetic information; c) remedies to compensate individuals for inappropriate use of genetic information; and d) incentives for further research and development in the use of DNA to promote public health, safety and welfare.

The findings of the Task Force reflect the complexity of issues surrounding genetic privacy and discrimination based on genetic information. Overall, the Task Force recognized that the research and development of new DNA-based technologies is proceeding at a rapid pace and providing knowledge and many potentially beneficial tools to medicine and public health.

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These technologies are also creating opportunities for researchers, insurers and employers to use genetic information in ways that were previously unavailable.

In light of these findings, the Task Force examined existing Washington State policies that may address genetic privacy and discrimination to determine if the policies adequately protect privacy and civil rights and provide incentives to promote the progress of potentially beneficial research and development. The GTF discovered that there are many facets to this question including, but not limited to, the debate over genetic exceptionalism and the absence of significant quantitative data regarding privacy violations and discriminatory actions associated with the use of genetic information. In general, Task Force members agreed that identifiable genetic information is personal information and the privacy of personal information is paramount regardless of who holds the information. They also agreed that the absence of quantitative data on the incidence of privacy violations or discriminatory actions does not necessarily mean that these acts do not occur. Instead, this finding may be an indication that: 1) victims or witnesses of discrimination do not report such incidents out of fear, embarrassment, or ignorance of wrongdoing; 2) the failure of authorities to recognize such incidents results from a lack of active surveillance, oversight or enforcement of program policies or existing anti-discrimination laws; and/or 3) the public, health care providers and researchers lack knowledge of existing reporting mechanisms and appropriate avenues for recourse.

Task Force also agreed that existing laws provide some protection against privacy violations and discrimination based on genetic information. However the members did not agree on the adequacy of these laws to protect individuals. Some members of the Task Force found gaps and ambiguities in existing laws that leave open the opportunity for privacy and civil rights violations to occur.

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The Legislature asked the Task Force to consider remedies to compensate individuals for the misuse of their genetic information. The GTF found that recourse and remedies for privacy or civil rights violations consist of reporting violations to administrative and/or oversight agencies and pursuing actions against perpetrators in court. Most of the laws reviewed by the GTF that are aimed at protecting an individual's civil rights and privacy provide for civil and/or criminal penalties in cases of wrongdoing. However, the Task Force noted that there is a dearth of case law specific to the misuse of genetic information on which to draw conclusions about remedies individuals claiming privacy violations or discrimination based on genetic information may receive from the court. In contrast, case law provides many examples of remedies for wrongdoing by health care providers, employers, or insurance companies in matters related to the broad issues of privacy and civil rights. Therefore, the GTF found that avenues for obtaining compensation or punishing violators exist within the current legal tort system.

Finally, the GTF evaluated incentives for further research and development in the use of DNA to promote public health, safety and welfare. Overall the Task Force found that incentives to continue genetic research and development exist in the form of funding and opportunities created by industry, academic and government research agendas.

The GTF developed the following recommendations for the Washington State Legislature regarding genetic privacy and discrimination and incentives to promote further research and development in the use of DNA to promote public health, safety and welfare. Some of these recommendations call for new legislation.

## Incidence of discriminatory actions based upon genetic information

### *Majority Recommendations:*

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1. Reports of predictive genetic testing should remain in medical records and receive the same protection as other sensitive medical information.
2. Authorize the funding of efforts by the DOH to educate consumers, research subjects, researchers, health care providers, employers, and insurers about how genetic information derived from DNA sequence, as part of medical information, can be used, the concepts and consequences of anonymity in research, and the reporting and other mechanisms available to those who believe they have been discriminated against.

## *Minority Recommendations:*

1. Create a policy to destroy tissue samples in the forensic database after DNA profiling is complete.
2. Adopt policies to outlaw genetic discrimination and protect genetic privacy, this would bolster peoples' confidence in the health care system, assuring that they have no hesitations about getting the diagnoses and treatments they may need.
3. Change Chapter 49.60 RCW to explicitly include "genetic information" in the list of characteristics that receive protection under the law.

## Strategies to safeguard civil rights and privacy related to genetic information

### *Majority Recommendations:*

1. Create policy to make all research involving human subjects in the State of Washington subject to the standards that are in place for federally funded human subjects research.
2. Develop a policy to ensure that subjects, health care providers, insurers, and employers have access to all existing laws (?) that protect the privacy of medical information, including DNA-based information.

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3. Leave the responsibility of monitoring research activities that involve human subjects to IRBs.

### *Minority Recommendations:*

1. Create a policy that requires destroying specimens collected from convicted criminals after they are tested and the DNA code has been entered in the criminal DNA database.
2. Enact legislation that explicitly defines genetic discrimination, genetic information, and privacy rights of individuals with respect to genetic information.
3. Revise the Uniform Health Information Act to ensure that genetic information obtained in the course of research participation is included in the definition of medical information.

### Remedies to compensate individuals for inappropriate use of genetic information

#### *Minority Recommendations:*

1. Pass legislation that protects the privacy of genetic information, defines and outlaws genetic discrimination, and provides avenues for redress when violations are proven.

### Incentives for further research and development in the use of DNA to promote public health, safety and welfare

#### *Recommendations:*

1. Given the limited nature of the data provided by testing conducted for the criminal DNA database, incentives for research using this resource are not warranted.
2. Ensure that state policy requires that in all research involving genetic information from individuals, explicit voluntary consent or assent be obtained, as detailed in current applicable law and regulations.

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3. Implement programs or other processes to educate the public, researchers, employers, and health care providers about existing measures to protect an individual's civil liberties and right to privacy. Such a program may reduce the perception that the risk of discrimination is high and encourage people to participate in genetic research.
4. Any process to create policies addressing the use of genetic information in research should invite participation from all stakeholders.

### Additional Recommendations

#### *Recommendations:*

1. Any infringement on an individual's rights to free choice regarding their DNA/genetic information is perilous and to be avoided in all but the most specific and compelling circumstances found in the newborn screening and criminal DNA database systems.
2. Give serious attention to establishing a graduate program in genetic counseling at the University of Washington to address the current and future needs of the State's population.